

POSTPOLIO SYNDROME: USING A SINGLE CASE STUDY

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ABSTRACT

The purpose of this study was to identify the major characteristics of postpolio syndrome (PPS), investigate physical and psychological limitations, and comprehensively review current medical interventions through a single subject design. The study addresses the symptoms and characteristics, the effect on life style, and the current recommended treatments of PPS. Also, suggestions for further research and links to rehabilitation centers specializing in post-polio syndrome research and treatment are included.

Poliomyelitis was first recognized as a separate and definite disease by the British physician Michael Underwood, in the latter part of the nineteenth century (Paul, 1971). Often referred to as polio, it gained the attention of the medical community and the population at large due to outbreaks in the late 1940s and early 1950s. Children were the most susceptible to contracting the polio virus (thus, the virus was often referred to as "infantile paralysis") because they did not yet possess the acquired immunity of the adult population (Melnick, 1996).

Poliomyelitis is an acute viral disease, occurring sporadically in epidemics, and is characterized clinically by fever, sore throat, headache, and vomiting, often with stiffness of the neck and back (Dorland, 1974). There are three types of poliomyelitis: spinal, respiratory, and bulbar (Paul, 1971; Saxon, 2001). Spinal polio is the most common variety. It is caused by an

infection of the spinal cord and results in a weakness of the limbs. The lower limbs tend to be more affected than the upper limbs. The second polio type is respiratory. With this form of polio, the virus attacks the nerves of the upper part of the spinal cord which controls breathing. The individual, therefore, develops difficulty in breathing and in other respiratory functions such as coughing, sneezing, and sniffling. A final polio type is known as bulbar. The virus affects that part of the nervous system that is situated just above the spinal cord known as the "bulb" or brain stem. This nerve center controls swallowing and talking, thus, the individual with bulbar polio has difficulty with these functions.

The poliomyelitis epidemic was finally contained in the United States with the advent of Salk's injectable vaccine in 1955 and Sabin's oral vaccine in 1961 (Halstead, 1998). Today, poliomyelitis is rarely evidenced in the United States although new cases continue to be reported in thirty countries in South Asia and West and Central Africa (Saxon, 2001). Insufficient immunization practices, despite the availability of polio vaccines, are often the cause of higher third-world incidence of the disease (John, 2000). However, polio-free nations such as the United States and Canada may be at-risk for importation of the poliovirus as immigrants, refugees, and illegal aliens enter the country from polio-endemic countries (Melnick, 1996).

While the general assumption is that polio in the United States was eradicated with the advent of the Salk and Sabine vaccinations, a fairly recent phenomenon known as postpolio syndrome has surfaced with the aging polio survivor population (Dalakas, 1995). It has been estimated that approximately 1.6 million people in the United States are polio survivors. Of this total, nearly 640,000 individuals contracted paralytic poliomyelitis (Parsons, 1995). The exact number of individuals with PPS is a matter for some conjecture. Some researchers have estimated that 25% to 75% of those who contracted paralytic polio would develop PPS (Saxon, 2001). Others have predicted that *all* persons who had paralytic poliomyelitis will develop some degree of postpolio syndrome (Falconer & Bollenbach, 2000). The purpose of the current case study was to identify the major characteristics of PPS, investigate physical and psychological limitations, and comprehensively review current medical interventions.

CHARACTERISTICS OF PPS

Postpolio syndrome (PPS) has been defined as new symptoms experienced by polio survivors occurring decades after recovery from the initial acute onset of polio (Saxon, 2001). The characteristics of PPS are similar to those found during initial onset. In fact, many individuals who had endured polio twenty

to thirty years earlier thought that PPS was actually a return of the poliomyelitis itself. The characteristics of PPS noted below do not all occur in each individual, nor do they occur at the same degree of severity. Research has shown that the following are characteristic of PPS:

- muscle and joint pain, and muscular weakness and atrophy (Agre & Rodriguez, 1990);
- unaccustomed fatigue (Berlly, Strauser, & Hall, 1991);
- breathing difficulties (Dean, Ross, Road, Courtenay, & Madill, 1991);
- cold intolerance (Bruno, Johnson, & Berman, 1985);
- sleep disturbances (Steljes, Kryger, Kirk, & Millar, 1990); and
- psychological stress from having diminished or lost functional abilities (Conrady, Wish, Agre, Rodriguez, & Sperling, 1989).

CAUSES OF PPS

While there is no agreed upon, single cause of PPS, several theories have been proposed. The most widely accepted theory proposes that after many years, overworked motor neurons begin to fail and are unable to maintain axonal sprouts created at the time of acute, initial onset of the poliomyelitis. These sprouts were created to compensate for motor neurons that were destroyed by the virus (Saxon, 2001). The failure of these neurons results in new muscle weakness and fatigue.

Another theory on the cause of PPS focuses on the supposition that the recovered motor neurons suffered cellular damage and are vulnerable to premature failure (Saxon, 2001). The combined effects of musculoskeletal overuse, musculoskeletal disuse, pain, weight gain, and other illnesses may also have influenced the progressive weakness, fatigue, and pain (Gawne & Halstead, 1995).

Finally, some investigators have theorized that aging, itself, might be a catalyst for onset of PPS. After the age of 60, most individuals demonstrate a decrease in the number of motor neurons in their spinal cords. Among polio survivors who have already lost a number of motor neurons, the age-related loss may compound previously existing muscle weakness (Dinsmore, 1998).

METHOD

This study uses a single case, qualitative approach. It relies on an interview which consisted of a structured format of a series of open-ended questions. An individual with postpolio syndrome, who was a colleague of the

researchers, was used as the case study subject. A mutually agreed upon time was determined for the interview which took place in the subject's home.

SUBJECT

The subject is a recently retired 62-year old married, white male who has postpolio syndrome. He holds a masters degree in counselor education and was the admissions director for a large, research university. He was diagnosed with spinal polio on July 17, 1952, two days short of his eleventh birthday. The subject experiences a general weakness in the left leg and has a pronounced contracture with paralysis in his lower left arm, wrist, and hand. He negotiates the day without the use of orthotics. The subject first noted the onset of PPS at approximately forty-seven years of age.

INSTRUMENTATION

Fifteen questions were developed based on the following themes: general demographics, education, employment, lifestyle, marriage and family, medical, personal history and treatment, functional limitations and adaptations, emotional status, and long-term care (see Appendix A). These structured questions were used as a guide to conduct an open-ended interview.

PROCEDURE

The open-ended interview was conducted over a single, two-hour time period. The researchers alternated asking questions of the subject to vary the format of the interview itself. The interview was audiotaped and transcribed to assure accuracy. Each of the two researchers proofed the transcription for validity. Additionally, one of the researchers wrote down the responses of the subject during the interview process.

RESULTS

The following results were gleaned from the structured interview of the subject with postpolio syndrome.

- The first symptoms included an extremely stiff neck and back, a high fever, accompanied with flu-like characteristics. A spinal tap was initiat-

ed to confirm the diagnosis of spinal poliomyelitis. Three days after initial onset of the polio virus, the subject's left side became weakened and partially paralyzed.

- The main treatments used with the subject in 1952 included: bed rest in the hospital, hot packs, turbo bath (similar to a Jacuzzi), physical therapy including stretch reflex exercises, especially with the fingers of his left hand.
- The subject's mother conducted recommended physical therapy at home for two and one-half years following initial diagnosis. Since there was little improvement with regard to the strength and grip of the left hand, it was recommended that the hand be amputated and replaced with a prosthetic hand. After due consideration, the subject disregarded this medical recommendation, in part, because he had some residual gross motor abilities in the left hand (e.g. gripping a steering wheel).
- Approximately fifteen years ago, the subject began experiencing the initial signs of PPS. These reported indicators included: significant fatigue, insomnia, a recurrence of residual weakness on the left side. Additionally, the subject's left leg, which had been 1/4 of an inch shorter than the right due to initial atrophy, increased to six to seven inches shorter as a continuing result of the PPS.
- Secondary traits that emerged as a result of the PPS were depression and weight gain. The depression was especially evidenced in two areas, his family life and his job. His spouse expected more than he could give due to his limitations of PPS. Furthermore, there was reluctance on his part to admit the problems he was experiencing due to the onset of PPS. He gradually began to lose interest in his job. This was especially evidenced in his becoming more sedentary, for example, traveling less for job-related duties. The weight gain was due to lessened physical activity which was brought on by the continuing atrophy resulting from the PPS.
- The subject reported that reluctance in updating his personal physician on his deteriorating condition was due to his being a husband and father of three children, and fearing what might happen to his life insurance coverage should the PPS condition become a part of his medical record.
- The onset of PPS limited his daily physical activities such as walking, jogging, engaging in yard work (he moved to a house with a smaller yard), driving distances of 50 miles or more, and other recreational endeavors such as dancing and riding horses.
- Due to his continuing deteriorating physical condition, the subject retired early at 61 years of age. Influencing this decision was the fact that the subject began to project his continued deterioration over the next

ten years and wanted to enjoy life while he had the physical ability to do so.

- Due to the fact that the polio vaccine became commonly administered only three years after the subject's initial diagnosis, he is a member of a relatively low incidence population of individuals with PPS. The subject recommended that more information be provided to employers and family physicians regarding postpolio syndrome. The reason for the information gap is that there is a paucity of PPS individuals as patients of physicians and as employees.
- The subject indicated that no medications were prescribed as a result of the onset of PPS. The only "prescription" he was given was the suggestion that he get plenty of rest.

CURRENT TREATMENTS FOR PPS

Current treatment of PPS involves both physical therapy and medication. Examples of these treatment approaches include:

- conservation of energy including alternate rest and activity periods and the use of assistive devices such as electric scooters for shopping in malls (Wenneberg & Ahlstrom, 2000);
- as much as possible, maintenance of normal, daily routine, with the modification of breaking down the activity into smaller time units;
- modified physical therapy (i.e. exercise tolerance limits are determined and implemented by a physical therapist so the client will not experience fatigue);
- regimented "passive" exercise (Gawne & Halstead, 1995) (e.g. swimming in warmer than normal water on alternate days);
- use of a nasal mask ventilator to assist with breathing and sleep disorders (Steljes, Kryger, Kirk, & Millar, 1990).
- diligent attention to weight control as excess pounds can stress involved muscles and joints; and
- administration of the medication *pyridostigmine* which is used to improve or help motor neuron growth (PDR, 2003).

DISCUSSION

Information gleaned from the subject interviewed in the current study confirmed previous research on postpolio syndrome. In fact, the subject's descriptions of living with PPS directly mirrored those traits found in the research

literature. These symptoms included fatigue, muscle weakness, sleep problems, depression, and weight gain. Conversely, the subject did not indicate any intolerance to cold, nor was he prescribed any medication to cope with PPS.

A key finding that affects a family "bread winner" such as the current subject is the matter of life insurance. With the present case, the subject felt that divulgence of the onset of PPS to his personal physician might affect his life insurance coverage, a particular concern for a husband and father of three children. This concern could also extend to the coverage of medical and long-term care where costs could increase due to onset of PPS.

The investigators speculate that much of the success of the subject's ability to cope with and adapt to life with PPS was due to his education and training. For example, the subject indicated that through his own research on PPS, he became more knowledgeable about the condition than his family physician. To this extent, the subject regularly reads a nationally published PPS newsletter.

The subject's self-initiated information gathering is related to another key finding of the current study. Poliomyelitis is a "forgotten" medical condition, with most health care and social service providers sharing the perception that the disease has been eradicated. This "out-of-sight, out-of-mind" perspective has led to those who survived polio and now suffer from postpolio syndrome being a "forgotten class" of individuals with disabilities. More information on PPS needs to be available to the medical profession (especially to family practitioners), state social service agencies, and medical and life insurance providers.

LIMITATIONS OF STUDY

The major limitation of this study is the caution against overgeneralization of the results of an interview with a single subject. This individual with an advanced degree and good job (prior to retirement) may be atypical of persons with postpolio syndrome. Additionally, since the subject was male, factors such as occupational success and family responsibilities may have reflected a gender bias.

IMPLICATIONS FOR FURTHER RESEARCH

With the aging population of persons with postpolio syndrome, research should be conducted to discern the effect of aging on these individuals' general well-being. Larger studies, national in scope, should investigate gender, ethnic and regional differences in the overall lifestyle of persons with PPS. Studies should be conducted to determine how medical and social service

agencies have adapted to provide support and information for persons with PPS. This information sharing could extend to national or regional networks since PPS is a relatively low incidence condition. A key issue that must be resolved for individuals with PPS is whether or not PPS, itself, is considered a "new" or pre-existing condition by insurance companies. Since PPS is a recurrence of the initial polio condition, it is likely that it may be considered a preexisting condition. However, due to the fact that it reoccurs after decades of time has past; it could also be considered a "new" condition. An obvious issue that needs to be addressed is obtaining a more accurate determination of the number of individuals with PPS. The literature varies from an estimated 25% to 75% of persons that contracted paralytic poliomyelitis. Due to this significant variability in the reported percentage of persons with PPS, an accurate and reliable data base needs to be established. Such a data base would be an invaluable resource for therapists, social services agencies, and family medical practitioners; not to mention a source for those who live with PPS on a daily basis.

APPENDIX A

Structure interview questions

- 1. At what age were you first diagnosed as having poliomyelitis (polio)?**
- 2. What do you recall were the first symptoms of your illness?**
- 3. How long a period did the polio episode last?**
- 4. What do you recall was the main treatment(s) for your illness?**
- 5. What were the residual effects of your illness?**
- 6. When did you first notice the symptoms of postpolio syndrome (PPS)?**
- 7. Describe the main symptoms of PPS that you have experienced.**
- 8. With the onset of PPS, were any accommodations or adaptations needed for normal daily living routines or work demands? If yes, describe.**
- 9. Describe any limitations in life activities that occurred due to PPS.**
- 10. Did PPS affect your retirement decision?**
- 11. What, if any, recreational activities were altered due to PPS?**
- 12. Describe any therapies or medications prescribed for your condition of PPS.**
- 13. What are your greatest concerns about your condition of PPS?**
- 14. As a result of your experience with PPS, what recommendations or advice would you suggest to health care providers, employers, and others in the community?**
- 15. Do you have any additional comments?**

APPENDIX B

Links to National PPS Centers

Mayo Clinic Jacksonville

<http://www.mayo.edu/mcj/MCJhome.html>

Roosevelt Warm Springs Institute for Rehabilitation

<http://www.rooseveltrehab.org/>

Spaulding Rehabilitation Hospital Network

<http://spauldingrehab.org/>

Sister Kenny Institute Minneapolis

<http://www.sisterkennyinstitute.com/>

The Post-Polio InstituteEnglewood (NJ) Hospital and Medical Center

PPSENG@AOL.COM

Bacharach Institute for Rehabilitation Post-Polio Center

<http://www.bacharach.org/services.htm#Post-Polio Center>

Charlotte Institute for Rehabilitation

<http://www.carolinas.org/services/rehab/CIR/index.cfm>

Albert Einstein Healthcare Network

<http://www.einstein.edu/>

University of Washington Medical Center

<http://www.washington.edu/medical/uwmc/index.html>

National Rehabilitation Hospital and Outpatient Center

<http://www.nrh.mhg.edu/>

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